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Original Research

Updated EORTC QLQ-C30 general population norm data for Germany

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Abstract ***Objective:*** The European Organisation for Research and Treatment of Cancer (EORTC) core questionnaire, QLQ-C30, is a frequently used patient-reported outcome (PRO) instrument to assess health-related quality of life of patients with cancer. To enhance the understanding and interpretation of PRO data, it is important to obtain norm data from the general population. This article presents updated general population norm data for the EORTC QLQ-C30 for Germany.

Methods: Data were obtained as part of a larger study collecting EORTC QLQ-C30 norm data across 15 countries via an online survey. After linear transformation of EORTC QLQ-C30 raw scores, data were weighted based on the United Nations' population distribution statistics. Data are presented by age and sex/age.

Results: A total of 1006 Germans responded to the survey. Across EORTC QLQ-C30 domains, different response patterns were observed, with men generally scoring better, that is, higher in most function scales and lower in most symptom scales/items than women. For age, mixed patterns were observed. While older respondents scored worse/lower in physical and role functioning, emotional functioning scores appeared to increase with increasing age. For the symptom scales/items, some symptoms were relatively stable across age groups, while

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others either increased or decreased with increasing age.
Conclusions: This study presents updated EORTC QLQ-C30 general population norm data for Germany that can readily be used for comparative purposes with data obtained from patients with cancer.

1. Introduction

Many short- and long-term constraints and side-effects resulting from cancer and its treatment are related to the subjective experience of the individual. Therefore, the assessment of patient-reported outcome (PRO) data is becoming increasingly important not only in oncological practice and research but also in the development and regulatory evaluation of cancer drugs [1–3]. However, the measurement and interpretation of patients' self-reported health-related quality of life (HRQoL) scores, a subtype of PRO data, come with methodological challenges, such as score interpretation. For example, to interpret scores and to understand how specific scores compare with other groups, a sensible comparator should be selected (e.g. other patients with cancer, norm data obtained from the general population and so on).

The European Organisation for Research and Treatment of Cancer (EORTC) core questionnaire, QLQ-C30, is a frequently used PRO instrument to assess HRQoL of patients with cancer. It covers 15 domains/aspects of HRQoL, including a global health/quality of life (QoL) score [4]. For the understanding and interpretation of EORTC QLQ-C30 data by use of a comparator, several efforts have already been undertaken. For example, for the comparison of EORTC QLQ-C30 data with data from other patients with cancer, reference values from various oncological populations exist [5]. Further, general population norm data are available for several European countries [6–14], including four studies on the German general population [15–18].

Despite the great efforts to generate general population norm data, the publication of various normative samples since the late 1990s has led to several challenges. At the national level, for example, different sampling strategies were applied across the four German studies, leading to differences between the studies [15–18]. In the context of multinational studies, uniform general population norm data are even more difficult to establish, unless HRQoL scores are obtained as part of a concerted data collection effort. A first attempt to provide summary European norm data was undertaken in 2014 by collating data from previously published studies [17]. However, this summary publication was not able to overcome the limitation of differences in sampling methods between the different studies. Consequently, to date, comparability of general population norm data between countries has been limited.

Owing to the lack of high-quality European general population norm data for the EORTC QLQ-C30, the EORTC Quality of Life Group decided to fund a large-scale cross-country project to collect norm data using a common methodology across 13 European countries. The aim of the study was to generate up-to-date norm data for the EORTC QLQ-C30 in a representative sample of the adult population in Europe. In addition, norm data were collected in Canada and USA for comparative purposes [19]. In this article, we describe the general population norm data sample collected from the German adult population. While national-level data have already been published as part of the core article [19], this article provides a more detailed overview of the German general population norm data by stratifying the sample by sex and age/sex. In addition, this article discusses similarities and differences compared with the previously published German general population samples that are adjusted using the same weighting procedure as for our data.

2. Material and methods

2.1. Item selection and socio-demographic data

This study was part of a larger study aimed at generating European general population norm data for the EORTC QLQ-C30 and its computerised adaptive test (CAT) version, the EORTC CAT Core [20]. The main study collected norm data in 15 countries in Europe and North America [19,21].

The 30 items of the EORTC QLQ-C30 cover 15 domains, of which five are function scales, nine are symptom scales/items and one is a global health/QoL scale. In addition, we collected data on sex, age, educational attainment, relationship status, employment status, presence of a range of doctor-diagnosed health conditions/diseases and ethnicity.

2.2. Sampling and data collection

Samples were stratified by sex and age. We defined five age groups (18–39, 40–49, 50–59, 60–69, ≥70 years), leading to 10 strata (female/male*age groups), with an anticipated sample size of n = 100/stratum. Data were collected via internet panels by GfK SE (www.gfk.com), a panel research company with long-standing experience with international surveys. GfK warrants panels to be

Table 1
Socio-demographic data of full German sample and sample stratified by sex (crude sample).

Sociodemographic variable	Full sample (n = 1006)		Females (n = 501)		Males (n = 505)	
	n	%[a]	n	%[a]	n	%[a]
Age (years)						
(mean, SD)	53.8	15.0	53.5	15.2	54.2	14.8
Age (years, in categories)						
18–39	200	19.9	100	20.0	100	19.8
40–49	201	20.0	100	20.0	101	20.0
50–59	201	20.0	101	20.2	100	19.8
60–69	201	20.0	100	20.0	101	20.0
≥70	203	20.2	100	20.0	103	20.4
Education						
Less than compulsory education	1	0.1	1	0.2	0	0.0
Compulsory (left school at the minimum school leaving age)	112	11.2	56	11.2	56	11.2
Some postcompulsory (some school after reaching school leaving age without reaching university entrance qualification)	396	39.7	222	44.5	174	34.9
Postcompulsory below university	163	16.3	85	17.0	78	15.6
University degree (bachelor's degree or equivalent level)	125	12.5	52	10.4	73	14.6
Postgraduate degree (master's degree, doctorate or equivalent level)	201	20.1	83	16.6	118	23.6
Prefer not to answer	8		2		6	
Employment status						
Employed full time	370	37.1	127	25.6	243	48.4
Employed part time	111	11.1	90	18.1	21	4.2
Homemaker	43	4.3	39	7.9	4	0.8
Student	24	2.4	17	3.4	7	1.4
Unemployed	31	3.1	17	3.4	14	2.8
Retired	333	33.4	171	34.5	162	32.3
Self-employed	60	6.0	23	4.6	37	7.4
Other	26	2.6	12	2.4	14	2.8
Prefer not to answer	8		5		3	
Relationship status						
Single/not in a steady relationship	170	17.1	76	15.3	94	18.8
Married or in a steady relationship	652	64.4	296	59.7	356	71.1
Separated/divorced/widowed	175	17.6	124	25.0	51	10.2
Prefer not to answer	9		5		4	
Health status[b]						
No health condition/disease	345	36.9	158	33.6	187	40.3
Chronic pain	270	28.9	156	33.2	114	24.6
Heart disease	74	7.9	32	6.8	42	9.1
Cancer (excluding basal cell carcinoma)	31	3.3	21	4.5	10	2.2
Depression	77	8.2	40	8.5	37	8.0
Chronic obstructive pulmonary disease (COPD)	34	3.6	15	3.2	19	4.1
Arthritis	152	16.3	99	21.1	53	11.4
Diabetes	118	12.6	47	10.0	71	15.3
Asthma	65	7.0	44	9.4	21	4.5
Anxiety disorder	37	4.0	17	3.6	20	4.3
Obesity	83	8.9	47	10.0	36	7.8
Drug/alcohol use disorder	10	1.1	1	0.2	9	1.9
Other	175	18.7	100	21.3	75	16.2
Prefer not to answer	*70*		*30*		*40*	

[a] Percentage excludes those who preferred not to answer respective question.
[b] Sum of health conditions/diseases is larger than the total sample of n = 1006, as respondents were able to check multiple response options.

representative for the general population in a given country. Data collection took place in March/April 2017. Further details on sampling, choice of countries, stratification and so on are reported elsewhere [19].

2.3. Statistical analyses

Socio-demographic data were analysed descriptively. Calculated mean scores of the 15 EORTC QLQ-C30 subscales were transformed to a range between 0 and 100 [4]. As a rough guide to determine group differences, we applied a cut-off of ≥10 points to indicate moderate group differences [22].

As the chosen sampling strategy was based on an equal number of subjects per sex/age stratum (Refer to Sampling and data collection), reported means based on the total sample were weighted by Germany's sex/age distribution to achieve that the 'German norm' was as

representative as possible of the German general population. Weights were derived from population distribution statistics for the year 2015 as published by the United Nations, Department of Economic and Social Affairs, Population Division population distribution statistics [23]. To enable accurate comparison of the new norm data with previously published German norm data [15–17], the weighted sex/age structure of our population was used to adjust the previously reported norm scores following the Hjermstad *et al.* [10] procedure.

We used IBM SPSS Statistics®, version 25, for all analyses.

3. Results

3.1. Sample description

As shown in Table 1 (crude sample), the sample consisted of 501 women and 505 men. The mean age was 54 years. Approximately 11% had less than or compulsory education, while about one third had a university or postgraduate degree. About one third was working full time, and one third was retired. About two thirds were married/in a steady relationship. Sixty-three percent of study participants reported having a doctor-diagnosed health condition/disease, with the most frequently reported diseases being chronic pain (29%), arthritis (16%) and diabetes (13%). As expected for a representative German sample with the given age structure [24], men had a higher educational level, and more men were in full-time employment compared with women, while more women than men worked either part time or were homemakers. Furthermore, more women reported to be separated/divorced/widowed and had at least one health condition compared with men (Refer toTable 1 for crude sample, Supplement Table 1 for weighted sample).

3.2. Overall HRQoL in Germany (weighted, unweighted)

Weighted mean scores for the function scales ranged between 73.9 (emotional functioning) and 84.8 (social functioning), while it was 67.0 for the global health/QoL scale. Symptom scores ranged from 6.0 for nausea/vomiting to 31.5 for fatigue.

To assess the impact of weighting on mean scores, weighted and unweighted scores were compared. As shown in Table 2, respective mean scores did not divert by more than 1.5 points showing minimal impact of the weighting procedure on the norm mean scores.

3.3. HRQoL by age

As shown in Table 3, data stratification by age suggested that physical and role functioning tended to deteriorate with increasing age, while particularly for emotional functioning, the reverse seemed to be the case. In the case of the latter, however, the youngest age group reported a relatively low level of emotional functioning compared with the other four function scales, with more than 10 points difference between respective subscale's mean score. For cognitive functioning, the youngest age group scored at least 5 points lower than any of the other age groups, with highest scores observed in the age group of 60–69 years. For global health/QoL, younger respondents showed highest scores (71.4 points), which monotonously decreased to 63.9 points reported by the oldest age group.

For symptoms, largest age differences were observed for pain, dyspnoea and insomnia, with younger respondents reporting substantially lower scores than older age groups. In contrast, the youngest age group reported higher nausea/vomiting symptom burden; they also tended to show highest symptom burden in appetite loss, constipation, diarrhoea and financial difficulties compared with older respondents with largely monotonous decreases of symptom burden from young to old.

3.4. HRQoL by sex and age

In addition to stratification by age, we further divided the sample into women (Table 4a) and men (Table 4b).

Table 2
EORTC QLQ-C30 general population norm data for Germany. Mean scores (M)/standard deviations (SD) by scales/symptoms, comparison of weighted[a] and unweighted scores.

Domain	Weighted		Unweighted	
	M	SD	M	SD
Function subscales				
Physical functioning	82.8	21.2	82.0	21.5
Role functioning	80.8	27.2	80.3	27.4
Emotional functioning	73.9	24.7	75.1	24.2
Cognitive functioning	83.9	22.7	85.4	21.1
Social functioning	84.8	25.5	85.1	25.5
Symptom subscales/items				
Fatigue	31.5	27.2	31.4	27.7
Nausea/vomiting	6.0	17.2	5.2	15.7
Pain	27.6	30.9	28.3	31.1
Dyspnoea	18.7	27.3	19.6	27.8
Insomnia	27.6	33.1	28.9	33.6
Appetite loss	10.1	23.3	9.3	22.2
Constipation	9.6	22.3	8.9	21.6
Diarrhoea	10.4	22.7	9.7	22.2
Financial difficulties	11.3	25.0	10.4	24.1
Global health/Quality of Life	67.0	21.8	65.9	22.2

EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer core questionnaire.

[a] Weighted by sex and age according to the United Nations, Department of Economic and Social Affairs, population distribution statistics for the year 2015 (United Nations, Department of Economic and Social Affairs, Population Division (2017). World Population Prospects: The 2017 Revision, DVD Edition).

Table 3
EORTC QLQ-C30 general population norm data for adults in Germany. Mean scores (M)/standard deviations (SD) by scales/symptoms stratified by age group (weighted data).

Domain	Total (i.e. men and women combined)											
	Total		18–39 years		40–49 years		50–59 years		60–69 years		≥70 years	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
Function subscales												
Physical functioning	82.8	21.2	87.0	19.7	87.7	16.9	82.9	21.3	78.9	21.9	73.6	23.4
Role functioning	80.8	27.2	84.7	25.1	84.6	25.3	80.2	26.5	77.7	28.4	73.0	30.3
Emotional functioning	73.9	24.7	69.4	26.5	73.8	25.1	71.9	25.6	79.1	21.7	80.3	19.7
Cognitive functioning	83.9	22.7	79.8	26.9	86.2	20.4	84.8	21.0	88.9	16.6	84.9	20.5
Social functioning	84.8	25.5	84.5	25.9	84.0	26.9	83.8	25.5	86.7	25.3	85.9	23.7
Symptom subscales/items												
Fatigue	31.5	27.2	31.0	25.3	33.5	27.7	30.8	27.3	29.2	28.1	33.1	29.1
Nausea/vomiting	6.0	17.2	9.7	22.2	4.2	15.0	4.9	13.6	4.0	13.1	3.6	12.6
Pain	27.6	30.9	21.9	29.0	24.4	29.0	29.9	30.3	32.8	32.9	35.0	33.1
Dyspnoea	18.7	27.3	13.7	23.4	16.1	24.5	18.9	27.2	23.2	29.2	27.0	32.2
Insomnia	27.6	33.1	22.1	30.7	26.9	32.1	32.1	36.3	30.2	34.3	32.0	33.0
Appetite loss	10.1	23.3	12.8	26.7	8.8	22.5	8.6	20.4	8.2	21.1	9.4	21.3
Constipation	9.6	22.3	12.3	24.9	8.4	23.1	8.6	19.8	8.2	20.5	7.5	19.8
Diarrhoea	10.4	22.7	12.7	23.7	8.5	21.4	11.8	25.6	7.4	18.8	8.9	21.1
Financial difficulties	11.3	25.0	14.0	28.0	10.8	25.4	9.9	21.9	9.5	24.2	9.3	22.1
Global health/Quality of Life	67.0	21.8	71.4	19.8	66.6	20.9	64.4	22.4	64.3	24.9	63.9	21.7

EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer core questionnaire.

The observed decrease of both self-reported physical and role functioning but increase in emotional functioning with increasing age was observed in both women and men. However, observed low scores for emotional functioning for the youngest age group were particularly pronounced in women who reported >15 points difference between this subscale and any of the remaining function subscales. For cognitive functioning, the observed peak in the age group of 60–69 years was only apparent in women, while the observed lower scores in cognitive functioning reported by the youngest age group were only seen in men. For symptoms, observed age differences regarding dyspnoea and insomnia were only apparent in women. In contrast, the observed age difference regarding higher levels of nausea/vomiting, appetite loss, constipation, diarrhoea and financial difficulty of the youngest age group compared with most other age groups was only found in men.

When comparing self-reported health between women and men globally, men scored slightly higher/better on the global health/QoL scale and the function scales, except for cognitive and social functioning compared with women. Men also scored lower/better on most symptom scales/items, except for nausea/vomiting and diarrhoea. However, when comparing respective total mean scores, none of these differences reached the *a priori* defined 10-point threshold, and only one subscale showed a difference of >5 points (pain, lower for men). When exploring each age stratum, however, some larger group differences were observed. For example, large differences were seen in the youngest age group in cognitive functioning with women scoring almost 10 points higher/better than men. Furthermore, women aged 50–59 years reported substantially lower/worse physical and role functioning and higher/worse symptom burden for insomnia, pain and dyspnoea than men of the same age group. Group differences in the next older age group (60–69 years) were substantially smaller, with the only marked difference observed for insomnia in favour of men.

Stratified results by sex and age are further shown in Fig. 1a/b (women) and Fig. 2a/b (men) for easier visualisation of the findings.

4. Discussion

In this article, we present updated general population norm data for Germany, which were obtained as part of a large, multinational study collecting norm data across 15 countries in Europe and North America, thereby applying a consistent data collection method throughout [19]. The application of a common methodology is particularly crucial to ensure that data can be compared across countries and cultures. For the purpose of this study, data collection was subcontracted to the panel research company GfK. Collecting data via internet panels is an efficient, cost-effective method to generate norm data, and there is evidence from a comparable study carried out by the Patient-Reported Outcomes Measurement Information System initiative that these data are representative of the general population. Nevertheless, this same group recommends weighting of scores to obtain a truly representative sample [25], a method which is consistent with our procedure. While weighting did not have a substantial impact on obtained mean scores in our study, the direction of score

Table 4a
EORTC QLQ-C30 general population norm data for women in Germany. Mean scores (M)/standard deviations (SD) by scales/symptoms stratified by age group (weighted data).

Domain	Women											
	Total		18–39 years		40–49 years		50–59 years		60–69 years		≥70 years	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
Function subscales												
Physical functioning	81.4	21.3	88.0	17.4	86.6	18.3	78.0	22.4	78.3	23.0	72.1	22.8
Role functioning	79.7	27.5	86.7	22.5	84.2	24.9	75.4	27.4	75.8	29.9	71.3	31.7
Emotional functioning	73.1	25.3	68.7	26.4	73.8	27.4	70.1	26.2	77.2	23.3	79.3	20.9
Cognitive functioning	85.2	21.2	84.9	22.5	85.5	22.7	82.5	20.1	90.5	14.3	84.3	22.1
Social functioning	85.7	25.6	87.7	23.8	84.7	27.9	81.0	27.5	84.7	28.7	88.0	22.1
Symptom subscales/items												
Fatigue	33.8	27.9	32.5	25.1	36.7	30.3	34.4	28.5	30.2	28.8	35.3	29.0
Nausea/vomiting	5.5	16.2	6.4	17.3	4.2	16.5	5.9	14.8	5.7	16.5	4.7	15.4
Pain	30.7	32.1	21.9	27.7	28.2	31.2	37.6	33.6	33.7	34.3	38.7	33.3
Dyspnoea	19.3	28.5	9.2	19.2	17.0	26.2	23.8	29.6	22.7	29.6	30.7	34.7
Insomnia	29.7	33.5	19.7	27.8	27.7	33.9	39.9	37.1	35.0	35.7	34.3	33.0
Appetite loss	10.7	23.4	10.1	24.4	10.7	25.0	10.6	20.5	10.0	24.0	12.0	23.0
Constipation	9.9	22.9	10.8	23.9	10.3	25.4	9.2	20.6	9.7	22.4	8.7	21.5
Diarrhoea	9.5	22.5	9.8	21.9	5.7	19.0	11.6	25.2	7.0	19.8	12.0	24.8
Financial difficulties	11.6	25.6	11.7	27.6	12.0	27.5	13.2	23.6	11.0	26.5	10.0	22.0
Global health/Quality of Life	65.8	22.0	72.3	18.2	65.3	22.3	60.1	22.8	63.8	26.6	62.6	21.0

EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer core questionnaire.

Table 4b
EORTC QLQ-C30 general population norm data for men in Germany. Mean scores (M)/standard deviations (SD) by scales/symptoms stratified by age group (weighted data).

Domain	Men											
	Total		18–39 years		40–49 years		50–59 years		60–69 years		≥70 years	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
Function subscales												
Physical functioning	84.3	21.0	86.0	21.6	88.7	15.4	87.8	19.1	79.5	20.8	75.7	24.2
Role functioning	82.0	26.8	82.7	27.3	85.0	25.9	85.0	24.8	79.7	26.8	75.2	28.3
Emotional functioning	74.7	24.0	70.1	26.6	73.7	22.7	73.7	25.0	81.2	19.8	81.7	18.0
Cognitive functioning	82.6	24.1	75.0	29.8	87.0	17.9	87.0	21.8	87.3	18.8	85.8	18.3
Social functioning	83.9	25.5	81.4	27.5	83.3	26.1	86.5	23.2	88.8	21.3	83.0	25.7
Symptom subscales/items												
Fatigue	29.1	26.2	29.6	25.5	30.5	24.6	27.1	25.8	28.1	27.4	30.0	29.1
Nausea/vomiting	6.6	18.1	12.8	25.8	4.3	13.5	3.8	12.3	2.3	7.9	2.1	7.3
Pain	24.3	29.3	21.9	30.2	20.8	26.4	22.2	24.5	31.8	31.6	29.9	32.3
Dyspnoea	18.1	26.0	18.0	26.2	15.2	22.9	14.0	23.8	23.8	28.9	22.0	27.9
Insomnia	25.4	32.6	24.3	33.2	26.1	30.4	24.3	33.8	25.1	32.2	28.8	33.1
Appetite loss	9.6	23.2	15.4	28.6	6.9	19.6	6.7	20.1	6.3	17.5	5.8	18.4
Constipation	9.2	21.7	13.8	25.8	6.6	20.6	8.0	19.0	6.6	18.3	5.8	17.1
Diarrhoea	11.4	22.8	15.4	25.0	11.2	23.2	12.0	26.2	7.9	17.8	4.5	13.3
Financial difficulties	10.9	24.4	16.2	28.2	9.6	23.3	6.7	19.5	7.9	21.7	8.4	22.3
Global health/Quality of Life	68.2	21.5	70.5	21.3	68.0	19.5	68.7	21.3	64.8	23.2	65.7	22.6

EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer core questionnaire.

adjustments was consistent with the higher weights given to older strata compared with younger strata, hence, consistent with age group differences reported in the Results section of this article.

Some of our findings are in line with response patterns that would be expected, such as the observed decline in physical and role functioning with increasing age. In contrast, comparatively low scores in cognitive functioning in young men were unexpected. However, this finding is in line with other studies suggesting that older adults frequently show a disconnection between subjective and objective memory performance and subsequently overestimate their cognitive functioning [26]. Coupled with possible downward comparison of the older ages groups [27], that is, comparison of oneself to people of the same age who are less cognitively able, as

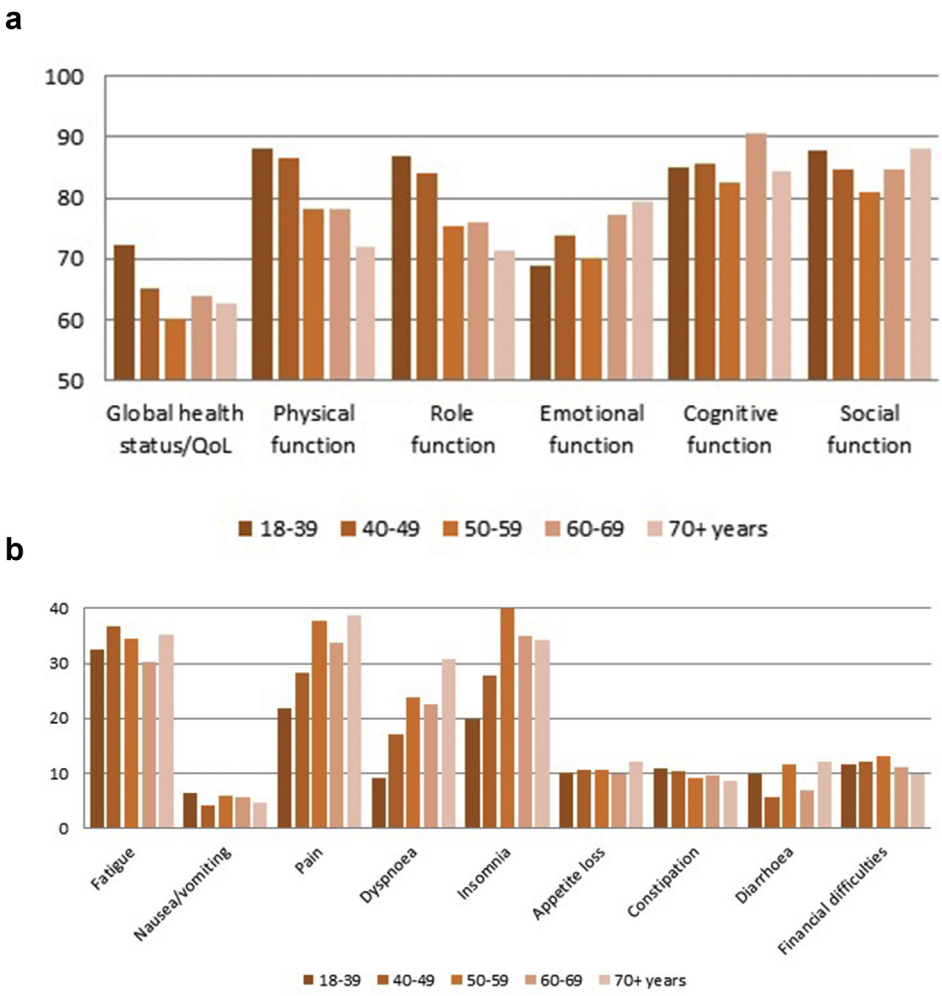

Fig. 1. a) German EORTC QLQ-C30 general population normative data for global health status/quality of life and function subscales for women by age group. b) German EORTC QLQ-C30 general population normative data for symptom subscales and items for women by age group. EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer core questionnaire.

well as with lower demands due to retirement, this might explain the relatively high self-reported cognitive functioning in older respondents. As our data were obtained via an online survey, it is also possible that older participants were biased towards those who were sufficiently (cognitively) capable and healthy to respond to an electronic survey.

For the EORTC QLQ-C30 symptom scales, some response patterns were again in the expected direction (e.g. pain and dyspnoea), while other symptom scales did not show any obvious trend. One exception was the observation of some consistently higher symptom burden in younger men (i.e. nausea/vomiting, appetite loss, constipation and diarrhoea) which may be related to differences in leisure activities (e.g. the high incidence of binge drinking, especially in younger men, might explain some of the findings [28]). In the context of symptom scales, however, it needs to be stressed that our sample is based on respondents from the general population and many symptoms are included in the EORTC QLQ-C30 because of particular relevance to patients with cancer during or after treatment. Therefore, some floor effects in the symptom scales in particular – regardless of age – can be expected when seeking responses to these items from the general population.

As earlier publications already established general population norm data for Germany, we compared our data to these publications [15–17]. Of note, we applied the same weights to the results from the earlier publications as applied to the data in this article to ensure comparability. First, it is striking that the general population data published by Schwarz and Hinz [15] and Hinz *et al.* [17] reported better scores (i.e. higher functioning/lower symptom scores) for all 15 EORTC QLQ-C30 scales than found in our data. For women, one function and four symptom scales/items showed deviations of >10 points. Even greater differences were seen for men, with four function and three symptom scales/items showing a deviation of >10 points. In

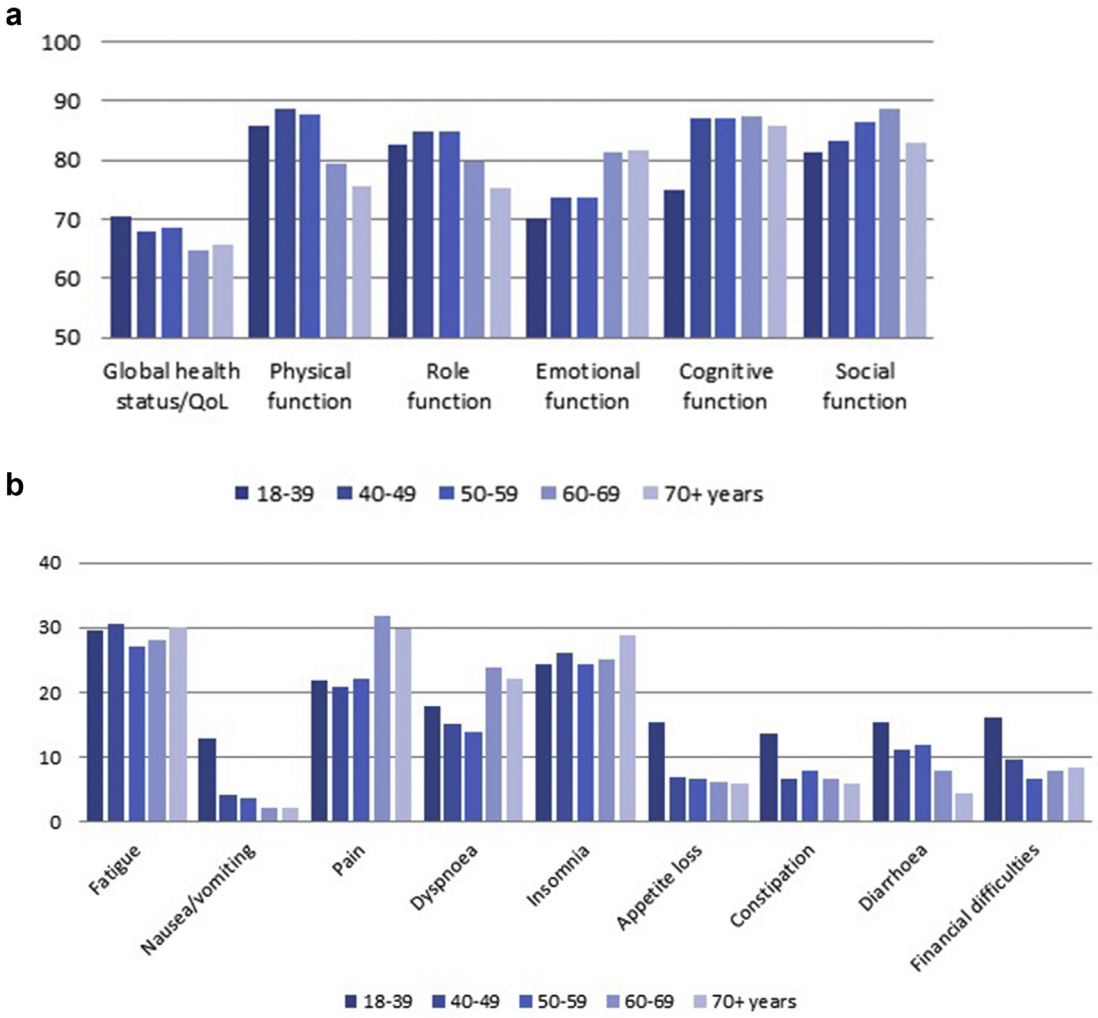

Fig. 2. a) German EORTC QLQ-C30 general population normative data for global health status/quality of life and function subscales for men by age group. b) German EORTC QLQ-C30 general population normative data for symptom subscales and items for men by age group. EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer core questionnaire.

contrast, normative data reported by Waldmann *et al.* [16] are largely in line with our data, with the only difference >5 points seen in emotional functioning in women (mean score 6.1 points higher/better in our data) and dyspnoea in men (5.0 points higher/worse dyspnoea score in our data) [16]. It appears that especially male respondents in the studies by Schwarz and Hinz [15] and Hinz *et al.* [17] reported high functioning scores with >90 points in all but the emotional function scale and comparatively low symptom burden compared with our and the Waldmann *et al.* [16] data. Hence, the former samples may have consisted of respondents who may have been too healthy to be representative of the German general population. To substantiate this notion, we compared our sample with national data collected as part of the German Health Update (GEDA) study, a large-scale health monitoring study in Germany with more than 20,000 participants [29,30]. Owing to space constraints, we cannot show all details of this comparison, but in summary, we found that the GEDA 12-month prevalence data of, for example, asthma (6.2% GEDA; 7.0% in our data set) and depression (8.1%; 8.2%) in the adult population are remarkably similar, while chronic obstructive pulmonary disease prevalence is even lower in our data set (5.8%; 3.6%) [29,30]. Sixty-three percent of our sample reported at least one health condition/disease (lifetime prevalence), with presence of a health condition being clearly associated with worse functioning/higher symptom burden (data not shown). We, therefore, believe that our sampling should have captured a more representative sample of the German general population compared with previously published samples.

This study has strengths and limitations. To our knowledge, the cross-country norm data project funded by the EORTC Quality of Life Group is the largest study worldwide to generate general population norm data for the EORTC QLQ-C30. These were generated across 15 countries in Europe and North America, thereby applying a common methodology. To achieve

quotas across countries, we subcontracted data collection to one of the largest panel research companies worldwide that ensure representativeness of their online panels. However, while we believe the sampling strategy via GfK's online panels is one of the study's strengths, there are limitations. Although internet access and usage has substantially increased over the last two decades, with 88% of German households having internet access, older citizens use the internet substantially less frequently than younger generations. While generally well over 95% of the German population between 10 and 64 years uses the internet, this percentage drops to 75% for men and 60% for women, respectively, in the age group ≥65 years [31]. Therefore, it cannot be ruled out that especially the oldest age group in our sample may not be representative of the general population of that age group. However, self-selection bias is not unique to our study but is a general concern in population-based surveys. For example, there is evidence suggesting that participants in health surveys report better health-directed activities and health status overall than those who do not participate [32,33]; however, another study found that self-selection hardly influenced scores [34]. In summary, while online surveys are not free of bias, alternative data collection methods come at the expense of other biases. For example, a serious concern in the collection of population data using alternative sampling techniques is non-response bias [33], which was not as much of an issue in our online panel [19]. Furthermore, one strategy to overcome a potential limitation of coverage error by means of quota sampling was to weight our data by Germany's sex/age distribution using the population distribution statistics published by the United Nations [23]. Therefore, while bias cannot be ruled out in any population health survey, the EORTC QLQ-C30 general population norm data for Germany presented herein are the best available data to date.

5. Conclusions

This study presents updated EORTC QLQ-C30 general population norm data for Germany assessed via an online panel. The current data show some discrepancies with earlier publications on norm data from the general German population. Following our earlier discussion, we are confident that our data collection as carried out by GfK yielded high-quality data. Furthermore, the data presented herein were gathered as part of a multinational study which comes with the advantage of enabling valid inter-country comparisons. In conclusion, this study presents updated EORTC QLQ-C30 general population norm data for Germany that we recommend using for comparative purposes with data obtained from patients with cancer, in particular also for use in multinational studies.

Ethical statement

Ethical approval was not sought as this study is solely based on panel research data. As opposed to medical research where medical professional codes of conduct apply, there is widespread agreement that health research involving volunteers from the general population is not subject to ethical approval. Both the European Pharmaceutical Market Research Association (EphMRA) and the NHS Health Research Authority specify that this type of research does not require ethical approval as long as the research conforms to ethical guidelines. Our online survey was carried out by the panel research company GfK SE which is a member of EphMRA. The multinational survey conformed to the required ethical standards by obtaining informed consent from all participants and collecting data completely anonymously. Any identification of the respondents through the authors is impossible.

Conflict of interest statement

None declared.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejca.2020.06.002.

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